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The Somali Community's Experiences with Autism: An Exploratory Study

Jessica Kuenzli

University of St. Thomas, Minnesota

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SOMALI COMMUNITY'S EXPERIENCES WITH AUTISM

The Somali Community's Experiences with Autism: An Exploratory Study

Submitted by Jessica Kuenzli
May, 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

School of Social Work
St. Catherine University & University of St. Thomas
St. Paul, Minnesota

Committee Members:
Sarah Ferguson, MSW, MA, P.h.D., LISW (Chair)
David Holewinski, MSW, LICSW, CBIS
Christina Krol, MSW, LGSW

Abstract

Recent studies indicate that children of immigrants are up to four times more likely to have an autism diagnosis than the general population (Barnevik-Olsson, Gillbert, & Fernell, 2008). Emerging research demonstrates that Somali immigrants are one of the immigrant groups disproportionately affected by the condition (Minnesota Department of Health, 2009). The purpose of this study was to explore how the Somali community experiences and perceives the condition of autism. The study consisted of interviews with community professionals who work with Somali families affected by autism. The findings of this research indicate that autism is a new concept for many Somali immigrants. The study found that the differences in views of childhood development between Somali and American cultures contribute to how Somali immigrant parents perceive autism. The study also found that Somali parents experience several barriers when accessing the service system. The findings of this study support the need for further autism education and outreach efforts to this population.

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Introduction

Autistic disorder, also known as autism, is a neuro-developmental disorder first apparent in infancy or early childhood. Key characteristics of the disorder include impaired development in social interaction, impaired ability to communicate, and a restricted repertoire of interests and activities (American Psychiatric Association, 2000; Black & Andreasen, 2011). Individuals with autism may exhibit a range of behavioral symptoms including hyperactivity, impulsivity, abnormal responses to sensory stimuli, and abnormalities in mood and affect (*DSM-IV-TR*, 2000). The *DSM-IV-TR* (2000) includes autistic disorder, along with four other conditions known as “Autism Spectrum Disorders” (ASD) in the broader category of pervasive developmental disorders. Of the disorders in this category, autism is considered the most serious and disabling.

The condition was first identified in the 1940s by Austrian psychiatrist Leo Kanner. Kanner termed “classical autism” as an “unusual condition characterized by social aloofness, impaired social interactions, disturbances in language development, and rigidity and problems with change” (Phetrasuwan, Miles, & Mesibov, 2009, p. 206). Over the next few decades, terminology for autism evolved to include names such as infantile autism, childhood schizophrenia, and autism psychoses (Phetrasuwan et al., 2009). Although understanding of the disorder increased during that time, it was not until 1980 that the American Psychiatric Association included the first clinical definition of autism in the *DSM*.

Autism was originally considered a rare condition, but researchers have noted increasing prevalence rates for several years. Autism now has a prevalence rate of about 10-15 cases per 10,000 individuals (Black & Andreasen, 2011), up from only four cases

per 10,000 individuals in the 1960s (Croen, Grether, & Selvin, 2002). The prevalence rate for all autism-spectrum disorders has been estimated as high as 110 cases per 10,000 individuals (Matson & Kozlowski, 2011). While the reasons for the increasing prevalence of autism are yet unknown, researchers have suggested that changing diagnostic criteria and better recognition of the disorder may be factors (Black & Andreasen, 2011). Nonetheless, the increasing rates of autism diagnosis have resulted in public health concern (Levy, Mandell, & Schutlz, 2009).

Autism is found in all races and social classes (Corcoran & Walsh 2009). Some recent studies have indicated, however, that children of immigrants are at an increased risk for the condition. Somali immigrants are one of the specific population groups recently found to have a higher prevalence over the general population. This trend has been established in the Somali population in Sweden for several years but was just recently established in the research in Somali immigrants in Minnesota, as well (Minnesota Department of Health, 2009).

The Somali began arriving in Minneapolis in the early 1990s as a result of civil war and political unrest in their home country of Somalia. Refugees from their East-African homeland, the Somali began fleeing their country in 1993, often spending years in refugee camps in Kenya before immigrating to North America and Europe (Kirby, 2008). Many Somali refugees eventually ended up settling in Minnesota, which now houses the largest Somali population outside of East Africa (Kirby, 2008). There are an estimated 30,000 to 60,000 Somali residing in Minnesota today (McNeil, 2009).

Several years ago, concern arose regarding the apparent disproportional rate of autism within the Somali population in Minnesota. Somali parents were especially

alarmed, as many had never heard of autism before. One parent, Hassan Samantar, as quoted to the *New York Times*, reported “there was no word for this in Somalia. People are calling it ‘otismo’ or ‘the American disease’” (McNeil, 2009). Similarly, the Somali population in Sweden refers to autism as “the Swedish disease” (Fernell, Barnevik-Olsson, Bågenholm, Gillberg, Gustafsson, & Sääf, 2010). The Somali community’s concern is not only about the prevalence of autism, it is also about the severity. Many feel that the form of autism occurring in Somali children is on the severe end of the autism spectrum – more “classic autism” as opposed to milder forms such as Asperger’s syndrome (Gorman, 2008). As a result of the growing concern, the state of Minnesota conducted a study confirming the disproportional prevalence of autism within the Somali student community in Minneapolis schools (Minnesota Department of Health, 2009). Despite this trend, however, very little is known about the connection between autism and the Somali population. Research has not explored the effect that autism has had on the Somali population, nor has it thoroughly explored what the Somali people’s perceptions and experiences are with the condition. This research, therefore, attempts to bridge this gap in the literature with an exploration of the way Somali immigrants experience and perceive autism.

Literature Review

General Risk Factors for Autism

While the causes of autism are yet unknown, several risk factors for the disorder have been established through prior research. The range of risk factors, as they will be described below, suggest that the cause may be multi-factorial, with the potential for both genetic and environmental factors involved.

Gender. Male gender has been established as one of the greatest risk factors for autism. Autism is diagnosed in males nearly three times as often as in females (Williams, Helmer, Duncan, Peat, & Mellis, 2008; Lauritsen, Pedersen, & Mortensen, 2005; Haglund & Källén, 2010). The DSM-IV-TR reports the risk of autism in males is as much as five times higher than in females. Furthermore, while males are more likely to be diagnosed with autism, females diagnosed with the disorder are more likely to exhibit characteristics of severe mental retardation (DSM-IV-TR).

Perinatal factors. Children with certain perinatal characteristics have also been determined to have an increased risk for autism. Several researchers have noted premature birth as a risk factor. For example, increased levels of autism were found in children who were born prior to 37 gestational weeks, as well as in children having a low Apgar score, low birth weight, and birth by elective caesarean (Williams et al, 2008; Haglund & Källén, 2010). The latter factors, by contrast, were only indicated as risk factors for autism and showed no associated risk for the related condition Asperger's syndrome (Haglund & Källén, 2010).

Parental age. Age of the mother at birth of child has been also been established as a risk factor for autism. However, it has been disputed at what age the risk begins. Haglund & Källén (2010) found maternal age over 40 to be a risk factor, while maternal age as young as 35 was found by Williams, Helmer, Duncan, Peat, & Mellis (2008). Paternal age has not been researched as much, however, one study found that paternal age over 35 was found to be a risk factor while but maternal age was not (Lauritsen, Pedersen, & Mortensen, 2005).

Family history. Children with a family history of autism are also at an increased risk for the disorder. Lauritsen, Pedersen, & Mortensen (2005) conducted a population study on 943,664 children, born in Denmark between 1984 and 1995, to determine risk factors for autism. Of the children in the sample, 818 were diagnosed with autism during the study's timeframe. While the authors identified several risk factors in that study, the highest risk was found for children with a sibling diagnosed with autism – 22 times the risk than for children without an autistic sibling. The risk for autism increased by 13 times when the sibling was diagnosed with a broader autism spectrum disorder. Another study (Minnesota Department of Health, 2009) reported that autism has a recurrence rate of between two and eight percent in siblings of children with autism – nearly 50 times the rate when compared to the general population.

Urbanization risk. Several studies have identified urban residency as a risk factor for autism. A study conducted in Denmark found that the risk for autism nearly doubled for children born in a capital city or suburb, compared to other areas of birth (Lauritsen, Pedersen, & Mortensen, 2005). The urbanization risk has also been associated with immigrant populations (Gillberg, Steffenburg, Bôljesson, & Andersson, 1987). Of the 20 urban autistic children included in the study's population sample, six (30%) had immigrant parents. None of the 15 rural children with autism included in the study had immigrant parents. The results should be taken with caution, however. The urbanization and parental immigration link could simply be due to the fact that immigrants are more likely to settle in urban areas for economic, social, and housing supports.

Parental immigration. A multitude of studies have shown that children of immigrant parents show disproportionate rates of autism in comparison to children in the general population. A higher prevalence of autism found in immigrant populations was noted as far back as 1980 (Wing). This trend has been established in immigrant populations residing in many countries, including Sweden, the United Kingdom, Denmark, Australia, and Minnesota. Although a few studies establish immigration by either parent as a risk factor (Gillberg & Gillberg, 1996; Gillberg, Steffenburg, Bôrjesson, & Andersson, 1987), most link autism risk specifically to maternal immigration (Gillberg, Schaumann, & Gillberg, 1995; Haglund & Källén, 2010; Keen, Reid, & Arnone 2010; Williams, Helmer, Duncan, Peat, & Mellis, 2008). An increased risk has also been noted when both parents were immigrants from different countries (Lauritsen, Pedersen, & Mortensen, 2005).

The majority of research done on the prevalence of autism in immigrant populations has been conducted in Nordic countries, primarily Sweden. Several studies done in the urban area of Göteborg, Sweden, suggest that maternal immigration is a risk factor for autism. Gillberg, Steffenburg, Bôrjesson, & Andersson (1987) conducted one such study and found that, of the 20 autistic children studied, six (30%) had immigrant parents. While that study did not focus on a specific immigrant population, a later study focused specifically on children of Ugandan mothers in Göteborg. Gillberg, Schaumann, and Gillberg (1995) found an increased prevalence of autism in Göteborg children born to mothers who emigrated from Uganda. The overall population of Ugandan immigrants in Sweden is small, and the prevalence of autism in the general Swedish population low. Within the timeframe of the study, 20 children were born to mothers who emigrated to

Göteborg from Uganda, three of whom were diagnosed with autism. The study, therefore, found a prevalence of autism in 15% of the Göteborg children with Ugandan mothers. The prevalence of autism in the general population at that time was 0.08% (Gillberg, Steffenburg, & Schaumann, 1991). Considering the small Ugandan population in Sweden, combined with the low prevalence of autism in that country, the results are noteworthy. However, the extremely small sample size should be noted as a limitation of the validity of this study.

The increased prevalence in immigrant groups was also found outside of Göteborg. Haglund & Källén (2010) conducted a study in Malmö, Sweden, that found a strong positive association between autism and maternal foreign birth. Interestingly, while the immigration factor was found to correlate to the condition of autism, a significant negative relationship was found between maternal immigration and Asperger's syndrome. The study also took paternal immigration into consideration, which, unlike maternal immigration, was not found to be a risk factor.

A Danish population study of children born between 1984 and 1995 also found that paternal place of birth, by itself, was not a risk factor for autism, but was a risk factor when combined with maternal place of birth. The risk for autism increased by 1.36 times for children who had both parents born outside of Europe, in comparison to children who had both parents born in Europe (Lauritsen, Pedersen, & Mortensen, 2005). Maternal place of birth had a significant role as the risk of autism increased by 1.42 times if the mother was born outside of Europe.

The risk of autism within children born to immigrant parents has also been noted in countries outside of the Nordic region, such as Australia and the United Kingdom.

Williams, Helmer, Duncan, Peat, & Mellis (2008) conducted a population study with a sample of 368 children in Australia and found that maternal immigration was a risk factor for autism. Of the various places of birth of mothers in the study, it was found that only those who were born in southeast or northeast Asia had the greatest prevalence of children with autism.

A United Kingdom study by Keen, Reid, and Arnone (2010) also found evidence of an increased risk of autism in children born to immigrant mothers. The study looked at both maternal ethnicity and maternal place of birth of 428 children diagnosed with autism or others autism spectrum disorders over a six-year period in the London area. There was an increased prevalence of autism in the children of mothers born outside of the United Kingdom, regardless of ethnicity. When ethnicity was considered independently of immigration status, autism was just slightly more prevalent in the children of African mothers than of Caucasian mothers. When factored in with maternal immigration status, immigrant mothers of African origin had at least a fivefold risk of having children diagnosed with autism or other autism spectrum disorders over the other ethnic groups.

“Exotic” country of origin. Not only is parental immigration noted as a risk factor in the available literature; country of origin of the immigrant parents has been found to have particular importance. Several studies have established an “exotic country effect” in relation to autism risk. In other words, the farther away the immigrant parent’s place of birth, the greater risk factor for autism. It should be noted that the term “exotic,” in this context, is used in the truest sense of the word – to highlight the vast dissimilarities between the cultures of the immigrant’s native country and his or her new country of

residence. The term “exotic” is not intended to refer to the culture or the country itself. The term “exotic country of origin” has been consistently used in this context in the literature, so its usage is retained in this paper as well. While the causes for the “exotic country of origin” effect are ultimately unknown, further discussion of this link is warranted.

A Swedish study found that the highest risk for autism was associated with maternal migration from outside of the Nordic countries, with non-neighboring or exotic countries having a higher risk. The highest risk for autism was found for children whose mothers were born in Sub-Saharan Africa (Haglund & Källén, 2010). The “exotic country effect” was also apparent in the study conducted by Keen, et al. (2010) in the United Kingdom. Of all regions of maternal birth included in the study, those from the Caribbean had the highest incidence of children with autism or autism spectrum disorders – at least five times that of children with mothers born in the United Kingdom. Maternal birthplace in Africa was second, and Asia was third.

While the trend of increased autism prevalence rates in immigrant populations has been widely noted in the research, the reasons for this are yet unknown. Several different hypotheses have been suggested by researchers. The most frequently cited hypothesis suggests that immigrant mothers are exposed to an infectious agent in the new environment to which they were not previously immune, and that agent subsequently damages the child's nervous system (Gillberg, Schaumann, & Gillberg, 1995; Gillberg, Steffenburg, Børjesson, & Anderson, 1987). However, no clear evidence of this has been found in the research to date (Gillberg, Schaumann, & Gillberg, 1995). Another common hypothesis is that the measles, mumps, and rubella (MMR) vaccination causes autism,

which was initially reported in 1998 by Dr. Wakefield (as cited in Matson & Kozlowski, 2011), however, that research has been since been discredited (Taylor, Lingam, Simmons, Stowie, Miller, & Andrews, 2002). A third hypothesis has been that certain genetic disorders may exist exclusively in the immigrant's native region and are thus passed on to the offspring of native parents (Gillberg, Steffenburg, & Schaumann, 1991). However, there is not sufficient research to support this conclusion. Most recently, researchers in Sweden hypothesized that vitamin D deficiencies in Somali mothers of autistic children residing in Sweden were to blame (Fernell, Barnevik-Olsson, Bagenhold, Gillberg, Gustafsson, & Sääf, 2010). The results of this study, however, were not significant and did not indicate any correlation between the two factors.

Immigration risk factor as it relates to the Somali

A recent trend emerging from the literature is the increased prevalence of autism within the Somali immigrant population. This trend has been established in studies conducted in Stockholm, Sweden (Barnevik-Olsson, Gillberg, & Fernell, 2008; Barnevik-Olsson, Gillberg, & Fernell, 2010) and in Minneapolis, Minnesota (MN Department of Health, 2009). While relatively little overall research exists regarding autism and the Somali community, the few studies published in the last few years have echoed the immigrant-risk trends seen in previous studies.

Barnevik-Olsson, Gillberg, & Fernell (2008) conducted a population study of children in Stockholm, Sweden born, between 1988-1998 that had a diagnosis of autistic disorder or Pervasive developmental disorder not otherwise specified (PDD-NOS) with a learning disability. The study found that the prevalence of autism or PDD-NOS was three to four times higher in Somali children than in non-Somali children. Somali

children were defined as children who “were either born in Somali or born in Sweden, with both parents born abroad and at least one parent coming from Somalia” (p. 598). The overall prevalence of autism or PDD-NOS was 0.2% in the entire child population, while the minimum prevalence within the Somali population was 0.7% and .19% within the non-Somali population. Of the Somali population studied, the majority of mothers had settled in Sweden prior to pregnancy and were living there during the entire course of pregnancy.

Barnevik-Olsson, Gillberg, & Fernell (2010) conducted a follow-up population study to their 2008 study and included the birth cohort of 1999-2003, with a total of 113,391 children living in Stockholm county, 1,836 of which were of Somali origin. The prevalence of autism was .98% in the group of Somali children, compared to .21% in the non-Somali group. The high prevalence found in the 2008 study was confirmed in the new birth year cohort. The prevalence in this cohort was 4.7 times greater than the general population. Because of an even higher prevalence of autism in the follow up study in comparison with the 2008 study, the research suggests a possible increasing prevalence of autism in Somali children born in more recent years.

A study conducted in Minnesota yielded similar results. The Minnesota Department of Health (2009) carried out a study in response to a suspected disproportional rate of autism within the Somali population in Minneapolis. The Minnesota Department of Health looked at the “administrative prevalence” of autism. “Administrative prevalence” involves analyzing the data of children who were eligible to participate in the Minneapolis School District’s Early Childhood Education Special Education Citywide ASD Classroom Program based on autism spectrum disorder

diagnosis. It should be noted that the study did not indicate the population prevalence, or actual occurrence, of autism within the Somali community, only the prevalence as it related to administrative records of school enrollment.

The study found a significantly higher administrative prevalence of autism in Somali children compared to non-Somali children enrolled in the program. This does not suggest that Somali children in Minneapolis have an actual higher prevalence of autism - it simply means that they are identified for and participating in the special education program to a greater extent than non-Somali children. There are several potential reasons for this that warrants further study: Somali children could be identified and/or diagnosed differently, there could be differences in outreach efforts between the populations, or there could be cases of “false positives” within children identified as eligible for special education services. There may also be children receiving services for autism spectrum disorders outside of the school district that are not accounted for in this study. The state’s recommendations for further areas of study included: exploring whether cultural differences play a factor in how children come into the system; whether differences exist in how developmental and behavioral problems are addressed between cultural groups; employing a population-based public health study of actual ASD rates within the state; and estimating state-wide and nation-wide administrative prevalence rates of ASD (a larger geographic area than considered in this study).

Multicultural Issues Related to Autism

Although autism has been found to occur across all races and social classes, there is minimal research exploring whether the concept of autism exists across cultures. Additionally, while the DSM-IV-TR designates autism as a mental disorder by its very inclusion in the manual, no consistent, cross-cultural definition of the term 'mental disorder' exists. Moreover, "no definition adequately specifies precise boundaries for the concept of 'mental disorder.' The concept of mental disorder [. . .] lacks a consistent operational definition that covers all situations" (DSM-IV-TR p. xxx). For these reasons, the next section will discuss multicultural views on various mental disorders and development disabilities, as they broadly relate to autism.

Cultural influences on the perceptions mental conditions. The concepts of disability and disorder vary amongst different cultures and religions (Zhang and Bennet, 2003, Pipher, 2002). Normal and abnormal behavior are defined differently by different cultures, and what is even considered to be a disability can vary greatly. For example, the western world classifies developmental disabilities and mental disorders using a medical model such as the DSM-IV. Rett's Disorder and Autistic Disorder are some examples of developmental disorders currently defined in the DSM-IV. Some cultures, however, may not even consider western-defined conditions as disabilities. For instance, the western label of 'mental retardation' does not exist in some Asian cultures (Cho, Singer, & Brenner, 2003). Furthermore, even the very idea of mental health conditions is foreign to many other cultures (Potocky-Tripodi, 2002).

There is also cross-cultural variation regarding views on the origins of disabilities. Some cultural/ethnic groups, such as Latinos, Asians, and Native Americans, believe that

family members or ancestors are responsible for the presence of disorders in their children (Pipher, 2002). As an illustration, having a disabled child may be considered punishment for one's previous sins (Welterlin & LaRue, 2007). Furthermore, there is much cross-cultural variation in the way childhood development is viewed. Across cultures, developmental milestones occur at different times (Pipher, 2002). American children, for example, are often toilet trained much later than Middle Eastern and Southeast Asian children. These different views towards what is considered to be normal development can also influence which developmental delays, if any, are seen as problematic across cultures.

South Asian parents have been found to cite lack of adherence to religious practices and poor health during pregnancy as possible causes of their children's autism (Jegatheesan, Miller, & Fowler, 2010). Other cultures view disability in a more celebratory light – that the birth of a child with a mental illness or developmental disability is a blessing from God. Another study found that Asian Muslim parents considered having a child with autism a blessing because Allah chose them to be special parents, and their children were gifts from god (Jegatheesan, Miller, & Fowler, 2010). The act of caring for disabled family members is also considered saintly in some cultures, with mothers of disabled children seen as akin to the Catholic Saint Mary (Skinner, 1999). Many other factors can contribute to a family's view on disability, including English proficiency, education level, socioeconomic status, immigration status, and degree of acculturation (Shu-mintuoli, 1995).

Because of the varied cultural beliefs about the definition and origin of disability, immigrants may be at particular risk for mislabeling by the dominant culture. Immigrants

may display behaviors considered “normal” in their native culture, but may be considered “abnormal” according to the world view of the dominant culture of their new country.

An example of this may be in the perception of how eye contact is viewed between cultures. In some Eastern and African cultures, direct eye contact is seen as disrespectful (Welterlin & LaRue 2007) whereas in the West, just the opposite is true. Thus, a person immigrating to a Western country who avoids direct eye contact may be mislabeled as rude. This phenomenon may translate into clinicians in the dominant culture believing a certain behavior of an immigrant is a symptom of a disorder when in fact the behavior is a learned cultural behavior. This is especially important as autism is often diagnosed according to deficiencies in communication and social interactions.

Cultural considerations in service delivery. Differences in the way disability is culturally conceptualized can lead to variations in the way early intervention services are provided to families with autistic children, as well as services sought by those families. Families who believe their child’s disability is the result of prior sins may prefer religious interventions such as prayer, sacrifice, and readings from religious texts (Basher, 2001; Welterlin & LaRue 2007). Other families may consult community elders for advice (Jegatheesan, Fowler, & Miller, 2010). For those families that do seek professional clinical help, several barriers to effective intervention and services exist (Zhang & Bennet, 2003). These barriers include the differences in language and culture between clinicians and patients (Welterlin & LaRue, 2007). The lack of ability to communicate with doctors can put families at risk for not getting the necessary information about their child’s condition. Clinicians may also not fully understand parents’ preferences for services if they cannot communicate with them effectively.

Researchers have made several recommendations for early intervention and special education professionals who work with culturally and linguistically diverse families. Developing goals that are considerate of the client's culture and language is crucial for family involvement (Zhang and Bennett, 2003). Also noted is the importance of providing information about the disability and the service options in a way that is culturally and linguistically understandable to the family. They also recommend identifying the family's strengths, resources, and specific needs in order to develop goals that are appropriate for the child's specific needs. Finally, Welterlin and LaRue (2007) note the importance of taking an eco-cultural approach to treating culturally diverse families. Their approach includes "incorporating components of a family's social and cultural environment to create a best fit intervention" (p. 756).

Somali Views on Mental Illness

While no studies were found investigating how the Somali population views developmental disabilities or mental disorders specifically, some studies were found that explored their views on mental illness in general (Guerin, Guerin, Diiriye, & Yates, 2004; Elmi, 1999). Until further research is conducted, the studies on the Somali's views of mental illness may provide insight into how they may view mental disorders such as autism. Indeed, it is unknown whether the Somali, or even the general population, are aware of the specific distinctions between mental disorders and mental illnesses.

Generally, mental illness is stigmatized in Somali culture. Mental illnesses are not easily accepted in Somali culture, and the existence of some conditions may even be denied altogether (Elmi, 1999). Moreover, Somali persons with mental illnesses risk being shunned from their community, and the fear of stigma often leads to social

isolation (Schuchman & McDonald, 2004). Guerin, Guerin, Diiriye, & Yates (2004) conducted a study to further explore Somali concepts of mental illness to determine how these concepts and beliefs influence the delivery of mental health services to this population. The authors found two primary categories of mental disorder within the Somali culture. The first category was that of serious madness, which is most similar to the Western diagnoses of schizophrenia or severe bipolar disorder. Similar to other cultures (Welterlin & LaRue, 2007), the Somali attribute these conditions to possession by spirits, ghosts, or “jin” (Elmi, 1999). This belief is largely tied to religious factors and interpretation of the Koran.

The second category relates to what the Somali see as a general lack of well-being, or general ill health. Western diagnoses akin to this category may be anxiety disorders and mild depression. This study, as well as others (Elmi, 1999) found that western concepts of stress disorder, such as PTSD and mild depression, are not present in traditional Somali culture. The Somali may attribute associated symptoms to ideas such as “not feeling themselves,” “feeling distracted,” or “not acting normal” (pg. 61). Conditions falling in this second category could include symptoms such as headaches, insomnia, and general forgetfulness. Even when these symptoms occur, the Somali usually do not think of them as serious and often ignore them altogether (Elmi, 1999).

Another finding of this study was that traumatic experiences or adverse events were often attributed to “God’s will” (p. 62) and thus not seen as requiring treatment or therapeutic intervention. This is very similar to other cultures’ attributions of mental disorders to religious factors (Welterlin & LaRue, 2007). Because of their spiritual conceptualization of mental illness, western treatment methods may not been seen as

effective to the Somali. They instead may prefer prayers and readings from the Koran (Guerin, Guerin, Diiriye, & Yates, 2004), over mental health counseling and drug therapy. Talking through problems, as is done in counseling, can be seen as a “frivolous luxury in the context of multiple other stressors that require more immediate attention” (p. 64). Any counseling that does occur is often done within the family or with community elders (Elmi, 1999). Schuchman & McDonald (2004) also stressed the importance of mental health treatment that is “congruent with the culture and religion” (p. 5) of the Somali population.

Similar to the studies already reviewed, Guerin, Guerin, Diiriye, & Yates (2004) also found several barriers to effectively treating the mental health needs of Somalis. One of these barriers is the Somali's heavy reliance on general practitioners. Somali persons often see their general practitioner, or family doctor, as the go-to person for all health needs. This may be due to the fact that, like many cultures, the Somali view physical, emotional, and mental symptoms as interconnected (Schuchman & McDonald, 2004), whereas the American medical model views these as separate health realms. They generally trust their GP in all matters and see it unnecessary to go to other specialists.

Language barriers have also been found to be a significant barrier. It has been suggested that agencies hire interpreters, utilize 24-hour language lines, or allow Somali clients to bring their own interpreter whenever possible (Guerin, Guerin, Diiriye, & Yates, 2004). The authors also note that it is important to not assume every interaction with a Somali client requires a translator. Automatically involving a translator in every interaction can be resented.

A third barrier in effectively working with Somali clients has been referred to as the “cultural mismatch in diagnosis, etiology, and treatment” between clinicians and their Somali clients. Western and Somali cultures often have differing views on the causes of and treatment methods for mental health issues (Schuchman & McDonald, 2004). Similar to Welterling & LaRue’s “ecocultural approach” (2007), Guerin, Guerin, Diiriye, & Yates (2004) suggest that professionals become more involved in the cultural communities they are working in so that they may become more knowledgeable about their clients’ belief and value systems.

Research Question

Studies have indicated that rates of autism have risen significantly over the last decade. One of the striking trends in the research indicates that children of immigrants are at an especially high risk of autism, up to four times the risk as children of native-born parents (Barnevik-Olsson, Gillberg, & Fernell, 2008). This trend has been demonstrated in several countries including Australia, the United States, Sweden, and England. Emerging research demonstrates that Somali immigrants are one of the population groups disproportionately affected by autism. While a few studies exist that explore immigrant groups’ views of autism, no researchers have asked how the Somali, in particular, conceptualize this condition. Moreover, little research exists exploring how immigrants experience autism, and no research exists to date specifically exploring how the Somali community experiences and perceives autism. Therefore, through the use of interviews with community professionals, the purpose of this study was to answer the question: What are the Somali community’s experiences with autism?

Conceptual Framework

Conceptual frameworks are important for research studies because they identify the principles and assumptions that guide the research. The conceptual framework for this study relied on assumptions from the theory of social constructionism (Gelles, 1999).

A social construction is defined as “an idea about the way things are, or should be, that is built more on the shared perceptions of members of a society than on objective reality” (Gelles, 1999, pg. 10). It therefore follows from this definition that social constructionism theory assumes that a society’s knowledge about the world is built on its shared social constructions rather than on an existing objective reality (Berger, 2001). Thus, a group’s subjective reality is created by its people through the on-going process of social interaction. People interact with each other, and through the use of language, shared cultural customs, and historical contexts, their mutual worldview (i.e. their subjective reality) is developed.

An important tenet of social constructionism is that the constructed social reality can vary between individual people as well as between different social cohorts (Berger, 2001). Social cohorts can be made of up many different groups of people, and sometimes there may be overlap between social cohorts. For instance, a social cohort could consist of a group of people of the same age, of the same socioeconomic status, of the same location, or of the same culture. Thus, social constructionism posits that each of these social cohorts may develop shared understandings and mutual unconscious knowledge of the world around them (Gelles, 1999). These shared meanings are the result of implicit social agreements and only exist within the context of a particular cohort.

Another important tenet of this theory is that social constructions can change over time. In other words, knowledge about the world evolves based on on-going interaction within one's own social cohort. Moreover, knowledge about the world can also evolve based on the interactions with other social cohorts. For instance, one group's social construction of an idea may have developed from a previous group's social construction, or definition, of the same idea.

In the context of this study, social constructionism theory was used to guide the assumption that mental disorders such as autism may be defined, perceived, and experienced differently by different social cohorts. The concepts from this theory were utilized in the development of interview questions and aided in the process of data interpretation.

Methods

Research Design

The design of this research study was qualitative. It explored the Somali community's experiences with autism through the use of semi-structured interviews with professionals who work with Somali families who have children with autism. Professionals who work with the Somali community were chosen due to the researcher's difficulties in obtaining referrals to Somali families who have children with autism. Due partially to a high level of stigma in the Somali community surrounding autism (personal conversation, 10/19/2011), Somali family members are often hesitant to discuss autism, or even disclose their child's diagnosis of autism, to people outside of the close family unit. Due to the limited timeframe available for conducting this study, the researcher

therefore chose to interview community professionals who work with this population, as access was considerably more convenient to obtain.

Due to the exploratory nature of this study, a qualitative approach was identified as most appropriate because of the greater depth of understanding that can be collected through the use of qualitative methods (Berg, 2009). Qualitative methods also allowed respondents to share their personal, subjective experiences in their own words. This research was conducted using semi-standardized interviews, which allowed for some flexibility in the wording, flow, and order of pre-determined interview questions (Berg, 2009). Seven individuals were interviewed for this research. Interview sessions lasted approximately sixty minutes each. Prior to use, the interview questions were reviewed by the researcher, the research chair, the committee members, and the University of Saint Catherine's Institutional Review Board (IRB) to ensure clarity and quality.

Sample

The target population for this study was community professionals that work with Somali families of autistic children and whom are knowledgeable about those families' experiences. Recruitment of participants focused on social workers, teachers, professional cultural liaisons (in schools and other community settings), professionals at local non-profit agencies, and other professionals who work with Somali families who have in the past, or are currently dealing with, autism. Eligible candidates were pre-screened to ensure they were over 18 years of age and had worked with Somali clients for at least three months.

The researcher used convenience sampling and snowball sampling methods (Monette, Sullivan, & DeJong, 2011) to recruit participants. This method relied on initial

identification of potential respondents from within the researcher's social and professional network. Initial respondents were asked to refer other professionals they knew who fit the eligibility criteria for the study and that were willing to participate in the study.

Protection of Human Subjects

Prior to conducting interviews, the respondents were given a consent form approved by the Saint Catherine University Institutional Review Board (IRB) (see appendix A). The consent form discussed the steps taken to protect the respondents from harm and outlined the ways in which the data was kept confidential. The consent form was reviewed with participants prior to starting the interviews and each participant was given an opportunity to ask questions about the study and procedures. The consent form included information regarding the intent of the study, the voluntary nature of the study, risks and benefits of participating in the study, confidentiality, and the researcher and school's contact information. Each participant was also told that they had the right to stop the interview at any time.

The interview questions were designed to be non-threatening in nature. Participants were also given the opportunity to choose the location of the interview. Interviews were audio-recorded and then transcribed by the researcher after the interview. No identifying information was included in the transcribed interviews. The audio-recordings and transcriptions were kept in a locked file cabinet and on a password-protected computer in the researcher's home. The transcriptions and audio-recordings will be destroyed upon completion of the project, no later than June 1, 2012.

Data Collection

Data for this research was collected using a semi-structured interview format, which allowed the researcher some flexibility in asking clarifying questions. Individual interviews were conducted with respondents, and each interview lasted approximately 60 minutes. Participants were asked a series of eight questions. The initial questions explored the respondents' job duties; the process of how families get referred to service providers; the process of how families obtain a diagnosis for their child; and the families' perceptions of the autism diagnosis. The latter set of questions explored the needs of the study's population and whether those needs were being adequately met. The final question provided an opportunity for participants to share any additional information that they felt was relevant to the topic and not yet covered in the interview.

Data Analysis

The data obtained from the interview was analyzed using grounded theory method. According to Monette, Sullivan, & DeJong (2011), grounded theory methodology is utilized when theory is developed as it emerges from the data, through the continual process of data collection, analysis, and theory development. In other words, the theory is "grounded" in the data. The researcher used this technique to initially code the data from the transcribed interviews using the technique of open coding (Berg, 2009). According to Berg (2009), open coding is described as combing through a dataset, line by line, searching for ideas and concepts produced from the data. The data was coded first for similarities and then for differences. The researcher then reviewed the codes a second time for patterns. As patterns emerged, the codes were then merged into larger themes. Codes that occurred two or more times in the data were developed into

themes. The transcribed interviews were then reviewed several times by the researcher to check for reliability.

Findings

This study utilized qualitative methods to explore the Somali community's experiences with autism. The sample for this study was community professionals who provide services to Somali families of children with autism. Seven individuals consented to participate and were interviewed for this research. The participants worked in a variety of community settings including schools and social service organizations. Three of the participants were Somali immigrants who work as interpreters in a local school district; two were special education coordinators/directors in the same school district, one was a school principal in a different school district, and one was a psychologist in a community-based practice. The sample consisted of five women and two men. Three Somali and four Caucasian individuals participated in the research. Participants in this study were asked questions regarding their Somali clients' experiences with autism, autism services, as well as their perceptions of the condition. Themes that emerged from the responses to these questions include the perceptions of autism in the Somali community, reactions to an autism diagnosis, the conceptual differences between cultures, and experiences in accessing the service system.

Perceptions of Autism in the Somali Community

Autism as a new concept. The idea that autism is a new concept to the Somali community was one of the themes that consistently came up throughout the interviews. Several participants mentioned that many Somali families had never heard of autism before immigrating to the United States. Participants also spoke of the lack of knowledge

that some Somali families have regarding the condition. One participant, that was Somali, explained how they were just recently introduced to the concept of autism within the last couple of years.

It's a scary thing. I don't know when autism started in our community, but I know when I started 4 years ago at the school district, I heard autism like crazy, like all the time. Autism this, autism that. I don't know if it just started five years ago, but I know, the day I started, that word was new for me. I graduated from [this school district], and I'd never heard of autism. So I wondered, what's going on, why are all our children, especially mostly the boys....what's going on here? We question that a lot.

Another participant, who was also from Somalia, echoed the same feelings:

I think it's something new to the community. They still don't figure out really why it's going on, and it's all over the place. But the problem is, nobody has figured out what's going on. Everybody is just waiting for an answer.

Many participants mentioned this sense of unfamiliarity with autism that many Somali families had before coming to the United States. Once they came here, they heard about autism frequently but often did not know what it meant or what was happening.

Perceptions of etiology. The idea that autism is a new concept for the Somali community has led to many theories within the community regarding why Somali children are disproportionately affected with autism. Most participants indicated that a lack of knowledge about the condition fueled some of these theories. In all of the interviews, participants commented that many of the Somali families they worked with questioned the cause of the condition and asked why their child was affected. Many also had developed their own theories as to why their children were affected. One participant commented about the beliefs of the families that she works with:

Whether they understand what it really means and so forth, I would say it's probably a good majority of Somalis who have heard of autism, whether they give it a name or not...think that it's something that's caused here, that it's an American problem.

That participant went on to say, *a large majority do think that it's some kind of condition that was caused by some factor related to them coming to the United States.*

As seen, the belief that autism was caused by something related to migrating to the United States was a prevalent theme within the findings of this study.

One participant explained some of the other theories that clients have mentioned regarding correlates of autism in the Somali community:

Yeah, there are different theories about it. Some say it's related to change in diet, some say its environmental exposures, some talk about some of the conditions that happened during the events that were happening in Somalia just before they came, but it's really, 'it wasn't happening there and now it's happening.'

Another participant commented on additional theories within the community:

Some of the families, even if they accept it, they're still asking why we're having these numbers of diagnosed kids, where is it coming from. Is it, like, we move from a hot climate to here, or is it the vaccinations....a lot of families, they're asking why we're having these [high] numbers. One day a mom said to me, "do you know that the kids who are born at the children's hospital, the Somali kids, most of them, they will have the disability, and the ones who are born in Hennepin hospital, they don't." I said, "Wow, I don't know about that." I said, "I have no idea." I just heard this a couple months ago.

Another participant spoke of the immunization concerns that families have mentioned.

A lot of my families believe it's the immunizations. Back home we never had shots at all, and now here you have to get all the shots before you start school. A lot of families are concerned, especially about the MMR shot. I see all these families saying "today, they were talking perfect, and they were just like a normal child, then they went in for the shot, and the next day they got sick and then that was the last time they spoke."

Another participant also mentioned immunizations when talking about perceptions of causes of autism in the Somali community: *You know, the talk about the immunizations, and the double-duty [of vaccinations] some of those kids may have gotten.*

These comments indicate that the Somali population has many theories as to how their immigration to the United States may have led to a development of autism in their community. These theories include immunizations, environmental toxins, changes in diet and climate, and factors related to migration stress.

Several participants mentioned that some of the families they work with have mentioned skin lightening creams as a possible correlate of autism in the Somali community. The creams referenced have been commonly sold at Somali markets and used by some members of the Somali community. One participant stated:

I've heard about the skin-lightening cream and about how people say it has mercury in it. So they say that, because of Somali parents using that a lot, because of mercury build up in the system, when the kid is born they have a lot of mercury and then it affects the brain.

The concerns regarding the skin lightening creams ultimately relate to families' concerns about mercury exposure and whether the mercury was the cause of their children's autism. Participants reported that parents were concerned that pregnant women would use the creams and their fetus would then be exposed to the mercury as a result. Regardless of the various beliefs of causes, participants explained that families often would focus on finding the cause of autism, sometimes at the expense of enrolling their child in services. One participant explained:

So, whether it's 'don't do vaccines,' or 'don't have your children while the mom is experiencing these conditions,' a lot of Somali families are convinced there's specific, finite problems that can be resolved and then this will go away. As a result, I think families end up kind of chasing the rainbow a lot, it's just an enormous mountain for families to climb to really understand what's going on.

Overall, participants reported that most Somali families were concerned about the causes of their children's autism and that many different theories exist within the community regarding the possible causes of the condition.

Reactions to Diagnosis

Several themes emerged from the data regarding Somali families' reactions to receiving an autism diagnosis for their children. Most participants noted that every family responds differently to getting the news of an autism diagnosis, yet some common themes were still present in the interviews.

Denial. The word "denial" was used by several participants when asked about how families' reacted to receiving an autism diagnosis. Families were reported to often initially react with denial when presented with the possibility that their child had autism. One participant commented, *In the beginning they are in denial, then they get to the acceptance stage, that yeah, something is wrong with their child, but before that they believe they will outgrow it.* Another stated, *when they first receive the news that their child is autistic....especially if it is something unexpected....they deny it, but eventually they will accept it.* One participant noted that denial was particularly note-worthy in those families who experienced their first intervention of autism services through the school system. *They don't go to doctors, and they don't have a word for autism, so they don't really know what's wrong with their child and then there's still this huge denial, that the kids will outgrow it, that they're just like other kids.*

Another denial theme that emerged was the Somali parents' belief that their child would outgrow the behaviors or delays that were symptomatic of autism. As can be seen in the quotes listed above, several participants mentioned that parents held this belief.

Somali families often initially responded to their child's autism diagnosis with denial, partially due to the fact that autism is a new concept for the Somali population and they believed that the child would outgrow the delays. However, parents were generally found to eventually reach an acceptance stage regarding their child's diagnosis, even if they initially denied the diagnosis in the beginning.

Anger. Two participants talked about the anger that some families feel when receiving an autism diagnosis for their child. When asked how families respond, one participant stated, *Anger. I mean, I think there's a lot of anger around it right now.*

We've had a few situations where there seems to be some angst about 'why is [the school district] identifying so many of our children?' Another stated,

You need to watch when you're saying to a parent, 'your child has autism, has that disability,' ... some families say, 'No, no!' So, I'll tell the nurse, 'we think there's something wrong, but I'm going to watch my mouth because I don't want to get that parent mad.'

Another participant explained that some of the parents' anger comes from not fully understanding the condition of autism and not understanding the signs of autism in their children. The participant explained:

I think there's a defensiveness and an anger about it being prominent in their community and we have those parents who say "you're off track, you don't get what you're talking about. I don't understand why you would see that in my child, he is not on the autism spectrum, I do not want to have this information shared with anyone."

Participants indicated that parents' responses of anger often were related to the fact that so many Somali children are receiving autism services, and that the Somali community has been affected by autism at a disproportional rate. Participants reported that parents, as a result, react with anger that this is happening in their community.

Isolation and stigma. Several participants noted that there is stigma

surrounding autism in the Somali community. This was a common theme in several of the interviews. One participant commented:

I think there are a great number of Somali families out there that don't want to have their child evaluated, aren't accessing services, don't want other families to know that they're getting services for their child, because of the stigma.

Another participant stated, *I know there is a huge stigma around mental health and autism in this community.* As a result of the stigma, some Somali families have a tendency to isolate from the rest of the community in order to keep their child's condition private. One participant explained that some families have refused home-based services because they don't want others to see providers come to their homes for this reason. Another participant echoed this same sentiment in the comment, *There is isolation in terms of not wanting other members of their community to know that their child has a special need, so that would be an isolation factor.*

One participant commented that, due to this isolation, there are likely families who are not receiving services for their children: *I think probably Somali community leaders might say that they feel that mothers and families are hiding and that there might be more children out there than we know.* Stigma around autism was frequently referenced by participants, and families were often reported to isolate themselves from the community to avoid the stigma.

Conceptual Differences between Cultures

Conceptualizations of childhood development. Another theme that emerged in the data was the difference between Somali culture and American culture's conceptualizations of childhood development and developmental delay. These differences in understanding the childhood development processes can lead to a

misunderstanding of the condition, and as one participant noted, may have an effect on whether Somali families know what to look for as behavioral indicators of autism.

I wonder how much typical development information [Somali families] have, and what they expect in terms play ... I think there are differences, and it occurred to me that some of the gap was maybe in understanding that there were very typical development milestones that we weren't seeing their [autistic] children meet. I really wonder ... if that's a little of the disconnect, that they're not knowing what to look for."

Another participant also spoke of differences in the cultural concepts of development and delay and explained that the differences can make it confusing for families to understand autism. It can also result in misunderstandings between Somali families and American providers. One participant commented that the word "delay" does not translate to mean the same thing between the Somali and English languages, so this can also lead to misunderstandings and miscommunications about autism and the developmental delays associated with it.

I think what's challenging is conceptually how different the cultures are as far as how we talk about these conditions and the understanding of it. I was talking to a Somali interpreter [...] and I discovered, in the most direct translation, "delay" means slower learning, but it doesn't imply that it's sustained and persisted slower learning. So, it can mean behind, but will catch up. And that's very different than when [Americans] talk about retardation or delay.

That participant elaborated by noting some of the challenges practitioners face in making sure Somali families understand the concepts and frameworks they are using.

The problem is that autism is not well understood in the community, and so there's a lot of myths that we have to dispel. [...] At the end of [an evaluation], we're on our way out the door, and a father says, 'does he have autism?' It's a really common response because the concepts are just very different and you have to start with some of those basic frameworks and make those very clear before families can really understand what we are talking about."

Another participant also referenced the idea that differing constructs of normal versus

abnormal development exist between the two cultures, and this sometimes becomes most apparent when the child enters school:

I think most of the families, they can feel that something is different with their kid, but they don't know what it is, where it's coming from, and then it's the doctor who first finds out what is going on or what's wrong with these kids. Then it's the school, because when they go to school they will find out right away that this kid is different than the rest of the kids.

A couple participants mentioned that what is diagnosed as autism in America was seen in Somalia as hyperactivity or just hyper behavior, and was considered a relatively normal characteristic of childhood. One such participant told a story of a past Somali community gathering:

I was at one workshop few years ago when this whole issue was first exploding, and there was a very revered Somali man there. The community was saying, 'we've never had autism before, there was no word for it back home.' And this, I thought, very brave elder statesman stood up and said, 'Yes, we did have this in our community, yes it did exist, you are right we never had a name for it, we would describe it as hyper...' and he was practically kicked off the stage, and he is a very well respected man. It just wasn't very well received.

Another participant also used the word “hyper” when talking about some Somali parents’ beliefs about the behaviors that doctors and school assessment specialists associate with autism:

...they believe they will outgrow it, that it comes within all of our kids, that it's something...like..... they just have ADHD..... we're all hyper in that way, so that's just something we believe in.”

Another finding was that the concept of disability was also mentioned as something that has variations in understanding between Somali and American culture. In Somalia, people with disabilities or mental illnesses were isolated and ostracized from the community. In America, however, many supports are provided to help include such individuals into society as much as possible. One participant explained this by saying:

Here, I see that even kids who have a disability, they have jobs, the schools will make them feel like they're equal. But back home, they were hidden. The kids who have some type of mental disability were, we'd say they were crazy ... you have to watch out for them because they're known as the crazy ones. But here in America, we don't think that, we give them help when they're young, and when they grow up they might even have a job."

Differences in the concept of disability also impacted the views some Somali parents have on the appropriateness of school-based intervention services. One participant stated, *In our community, we think special education is only for kids in a wheelchair. You know, here that's not true, so it's hard to explain it to a family.* Because services were typically not provided to disabled or mentally ill persons in Somalia, Somali families may not associate the developmental delays of autism with the need for special education services. The lack of association between these two concepts was commonly reported by participants as a challenge often facing practitioners.

Differences in socialization of children. Several participants addressed some cultural differences in the way young children are socialized into society. One Somali participant commented that, due to recent immigrants' general unfamiliarity with their new neighborhoods and environments, children are often kept at home more frequently than they were back home in Somalia. One participant explained that the winter climate in Minnesota is unfamiliar for many Somali families who are used to a warm climate, and therefore kids are kept inside most of the winter. As one participant noted, even the parents rarely go outside in winter, so this has an effect on the exposure Somali children have to interacting with others. Another participant noted that Somali families sometimes tell their children not to play too much in fear that their apartment neighbors will complain. Therefore, when Somali children get to school they want to run and play

with other children, but the schools expect that they practice more restraint and focus on education.

Another Somali participant discussed the ways in which the demands of American culture and society have an effect on both the opportunities for children to interact in society and on the expectations of how children should act in society. The participant commented on the differences between Somali culture and American culture such as child rearing:

My own mom had seven kids, and . . . [T]he whole neighborhood would help her out. She could go to work and she would leave us with the neighbors, or she would leave us at home and the neighbors would keep an eye on us, it's fine. But here, it's tough. I have a daughter, and I work all day, [and], you just don't want her to even interact with other kids there because you don't know how that parent there will feel about it. Where back home, that would have been just fine.

Another participant stated, *I think there's a socialization component, that the kids are not getting out and socializing. Although they do meet with families in their community, you know, but they're not interacting with the outside community.* Participants reported that they felt it was important for Somali children to get outside and interact with children outside of their community so that they were better prepared for the school environment.

Effects on enrollment in services. The differences in constructs of normal childhood development between cultures was also reported to have an effect on the age level at which children were enrolled in autism services. One participant, who does early childhood special education screening, spoke of these delays as related to the cultural differences in understanding the childhood development process.

When the kids are referred to us, a lot of families wait [to bring them in], we accept three to five year olds, but a lot of my families wait to come in until their child is five. A lot of families are in denial at the beginning, because in our culture, we believe that, especially boys, that it's fine for them to run around, it's

something that's just within us. Something that's natural. So a lot of families say, 'Oh, it's nothing, it's nothing, he's young, he's a baby, he'll outgrow it.' And then they have to start kindergarten but this child still isn't making eye contact or does not sit still or does not talk, then the families get really concerned.

Families' delay in enrolling children in services due to lack of understanding of normal developmental milestones was also mentioned by another participant.

I think the first time in all families, it's very hard to accept, and then, when they hear the first time, they want to take their time, wait one or two years to make sure everything that they're hearing is right and correct. And then after that they don't have any other choice and then they have to accept service.

Another participant commented that sometimes parents choose to wait to enroll their children in special education services because they want to see if the problem goes away on its own. The participant explained that families will wait about six months to a year to see if there is any change in the child's behavior. Then, most of the time the parents come back to the school the next year and consent to do an individualized education plan (IEP) assessment, because by that time they understand that the problem isn't going away on its own.

Perceptions of Delayed Speech. Participants noted that while Somali and Western cultures may disagree on when a diagnosis of autism is appropriate, both cultures often mutually view delayed language development as a problem. Thus, even if Somali families have a hard time understanding the Western structure of childhood developmental stages, communication and speech is something that they've found to be a much more universal concept. One participant stated,

I think that our struggles are always around the social and play area and trying to communicate with the parents an understanding of how different their child is [in these areas]. But, they get communication because communication is concrete, and they can see that their child isn't using words and putting words together, not understanding, not responding to their names, and that is much more concrete.

Because speech delays are easier understood by Somali families, participants reported that it was often the primary, and sometimes the only, reason families sought autism-related services for their child. One participant stated, *Families' primary concerns are usually around language delays. That's probably the first sign to them to access services.* Another participant stated, *Many times the families' first concern is around language development - as they get older, it becomes clear to them, or sometimes when they are young even, that there are differences in how the child interacts in the world.* Participants noted that, even when providers told families that their child had autism, some families would still only accept speech services because this was the only developmental area that they perceived to be a problem with their child. One participant stated that families have often told her, *it's just speech, it's not autism, the language is all we need help with, nothing else, and not autism...they'll repeat it over and over.*

Participants commented that they often utilized the mutual concern over communication delays as a way to draw families into the service system. One provider stated,

There can be a barrier over the label [of autism]. We try to not lose them in the process, and we try to gently massage it, if you will. So we'll say, it's a developmental delay no matter how you want to slice or dice this. If it's more comfortable for you look at receiving services for your child under that more global developmental delay, please stay with us and we can provide services related to that. We never want to lose a family over an autism label...we want to keep the relationship going.

That participant went on to explain the importance of keeping families engaged in the system. Even when they are initially brought in under a language delay label instead of an autism label, providers focus on keeping the families reeled in and gaining their trust

in the process and in the system. Once that happens, providers often will try to re-address the autism concerns with families at that point, and often do so successfully.

Accessing the Service System

First point-of-service. Participants reported variance in the ways Somali families first access the system for autism services: some receive a diagnosis through a medical doctor, while others are first made aware of their child's condition through the school system. One participant stated, *It can be kind of two-fold, it can be that [the school district is] the first access point to services or it could be that basically through the medical realm their child has been identified by a physician as having some concerns.* Several participants felt that the education system was most often the first point-of-contact for students. If the school-based assessment is the first indicator of developmental concerns, school staff will often then provide a referral for the child to see a medical doctor to get a diagnosis confirmed. One participant explained that this may be because Somali families are more familiar with the school screening process than the medical diagnostic process: *A lot of families, especially if they have been here for a while, are familiar with the preschool screening process and that their child needs to get screened before they start school.* Participants generally agreed that the preschool screening process was the first line of intervention for Somali children, and that at least 50% of the families they worked with had come through the school system first.

The age of the child was one factor that participants reported had an influence on where the initial point of service came from. Participants explained that younger children were more likely to be first identified by doctors and then referred to school-based

services, partially due to better screening tools and education that have recently been provided to doctors. One participant stated,

Generally, with the younger population of students, birth to 3 years old, there's a good system for signs in place, where physicians at clinics are trying to be more proactive, and patients are receiving education in terms of identifying children earlier rather than seeing families and saying, 'just wait, it's just a boy.'

Also regarding younger children, another participant explained that the behavior and speech exams provided at medical facilities can often catch children at a young age, usually around the two-and-a-half year mark.

An important distinction that emerged from the data was the fact that families who have gone through the medical system often receive an official diagnosis, whereas families who have accessed only the school system may not have an official diagnosis because the school doesn't diagnose. One participant, a non-school based psychologist and clinician explained, because of this, the schools might not convey the seriousness of autism:

For example, because often kids will come in, and medically it may be clear that they qualify for an autism diagnosis, but the schools are more likely to classify them in categories like developmental delays. Even if the schools are, to their credit, very clear that they don't diagnose and simply are an educational strategy, it doesn't say anything about the underlying disorder. Schools talk about autism strategies or educational approaches, families are still often unclear about the condition their child has.

The fact that the school system doesn't officially diagnose children with autism and is usually only the educational component can be a source of further confusion for families. Participants suggested that families who receive only school based services may, as a result, get the mistaken impression that their child's delays aren't in fact serious, and may not even be autism.

School and medical systems viewed as separate realms. The source of the diagnosis also plays a role in how and when families get connected to intervention services. Those that are diagnosed at an early age by a doctor are often referred immediately to school-based intervention services. Those that are first identified through the school system, however, often seek a doctor's opinion to verify the school findings. One participant stated, *One of the things I have noticed, if the family gets a diagnosis from a doctor, it's easier for them to accept the diagnosis at school. But if the diagnosis comes from the school, the families usually want to corroborate it with a medical doctor.* Another participant explained that this may be the result of Somali families not understanding the connection between school-based services and medical-based services. The participant explained,

I think for Somali families, the doctor and the school is two different things. There is no connection back home between them. So, since it's a medical thing, they ask why the school thinks it's a problem, why is the doctor not saying it's a problem? How does the school know about these things? Also, with Somali families, when the school is doing an assessment, when they hear about psychology, they ask what a psychologist is doing inside the school. It's very difficult to explain...it's not something that they know.

Another participant made a similar distinction between Somali families' understanding of school services versus medical services. The participant explained that, back in Somalia, disabled children were often kept out of school altogether:

A difference is, back home, parents had to deal with the doctor, not the school. And a lot of kids who were disabled back home, they used to stay home, because there's no service in the school for those kids. So, the difference here is the parents are dealing with the school also. It's difficult for them to understand.

Another provider spoke of the same idea when explaining some of the challenges encountered in getting families connected to school-based services. The participant commented that, because Somali families view the school system and the medical system

as completely separate, they may not understand that the school system here has services available, and they may not understand how those school-based services can help their child.

Barriers within the Service System

Nearly all of the service providers interviewed for this research spoke of the barriers that Somali families often face in entering, navigating, and utilizing the autism services system. These barriers include lack of knowledge regarding intervention and treatment services, disconnects in-and-between the service sub-systems, and language barriers.

Lack of knowledge regarding services. Many participants mentioned that the Somali families they work with often do not understand that there are services available here to help children with autism. One participant explained this as a lack of understanding and awareness regarding the benefits of treatment services:

Families may receive some kind of diagnosis or evaluation, but they don't always get the service or treatment. And part of that is not understanding, 'what does this treatment do for me?' They don't know what it looks like, they don't know what happens, they don't know how it's gonna help, it doesn't make any sense to them. So accessing service has to, at its most basic component, has to be an awareness of what that is.

Another participant commented on the need for providers to help families understand the availability of services and what those services will look like:

There are needs to help them make the translation from 'I know there's something wrong with my child' to 'I want help for my child' to 'here's the place you can get help, and here's how it will work.'

One participant commented on the importance of families having the knowledge of what services might be available to them. The participant explained that there is a disparity in the system between the families that know what's out there and the families that don't.

For the families that aren't familiar with services, they often don't even know to ask for help or what sorts of help to ask for:

Some of the families might be receiving a lot of good social services support, and maybe [personal care assistance] and the child is in school full time, and then there's other families who are absolutely managing it all on their own. It's a fact of the disparity of how families are able to access services. If you don't know what's out there, you don't understand that there's a social work system that can help. It's very hard to know.

Several providers commented on the need for increased education and outreach to Somali families in order to reduce this disparity and to help get families connected to services.

Disconnects within the service system. Another common theme regarding the service system was the disconnect between providers within the system – namely between the county, the schools, and the medical system. Each of these subsystems provides certain autism services, and participants often explained that connection between these systems is crucial for effective and efficient services. One provider explained the distinct services available from each sector: *The county can provide PCA and help with financial resources, the medical clinic can provide diagnosis, which you need to get SSI [Supplemental Security Income], and the school can provide education services.* Participants frequently expressed frustration regarding the disconnect between these systems. One participant summed this up in the statement:

A fault of the system is that we don't hand off families from one point of service to another point of service. We're very much a culture of silos and brochures and much less a culture of relationships and that's just an enormous problem with families being able to get the next step they need, or getting other services.

Another participant spoke of the frustrations the school system experiences when trying to help families access county-based services:

Families get frustrated trying to access services. I feel like, you know, as the school, we can only take the kids so far, but when it's accessing community services, we get no help from the county. They're constantly switching case workers, or the case workers don't show up. That part is very frustrating for all of us.

Several of the school-based participants that were interviewed expressed the same frustrations in trying to connect families to services provided by county agencies and medical providers. Another participant explained,

We only have our finite resources and what we can say is we can do this, and we try to coordinate and communicate with the medical and county agencies, but we need strong communication and support. These other agencies have to step it up to help support us, too. We can't be the end all, be all, just by ourselves.

Overall, participants were frustrated with the lack of follow-through in the system between one service provider to the next. Participants commented that there needs to be a better system in place so that families have a smoother experience when transitioning from one are of the service system to the next.

Access to interpreters. The largest barrier that Somali families face in accessing autism services, according to interview participants, is the language barrier. Access to well-trained interpreters is essential when providing quality services to limited-English speaking clients. One participant explained,

Language is a huge institutional barrier, because, I mean, I can't do what I do without someone who can interpret what I'm doing. And if that person isn't good, then my service isn't good. That language is the segue to being able to communicate about what is happening.

Nearly all participants commented on the need for more interpreters to be available for Somali families who are not fluent in English. One participant commented, *language access is huge. If you can't call someone in your language and schedule appointments or ask them about what's happening to your child that day, it's a huge barrier.* Participants

noted that it is important not only for providers to have interpreters available for Somali families that want them, but also that interpreters be trained and knowledgeable about the resources available in the system and how the system works. One participant commented:

We need to have not only bilingual, bicultural providers, but we need to have good interpreters. They need to be on site and available at all times. They need to be partners in the care. And part of that needs to be providing ongoing patient education the process.

Another participant commented on the particular need for interpreters outside of the school system:

One huge barrier is language. The school district has interpreters, but some other places, it's hard to find interpreters, and even if they have interpreters, they might not be trained enough. That creates too many barriers for families to move around in the system. Families need to learn the basics before they can move on to what they are entitled to get and how they can then access those services.

Participants generally agreed that the schools were doing a good job providing on-site and culturally appropriate interpreters for the families they were serving, but that there was a significant lack of well-trained, effective interpreters available in other areas of the system.

Interpreters as facilitators into the system. The use of culturally compatible interpreters was found to be helpful in building the trust of Somali families and getting their buy-in to treatment services. One participant explained that, for many Somali families, having someone of their culture who can facilitate communication between the service providers and the family, and doing so in a culturally sensitive way, can help build the trust of families.

Without having an interpreter, the worker is not usually a face right away that the family would recognize. We usually have a Somali interpreter that is right there,

and that face is part of when the team is going out to meet with parents. It's not going to happen unless we have that support.

Several participants reported that having trained Somali staff members as a visible part of the service delivery team was important in gaining Somali families' trust and acceptance of autism related services for their child.

Discussion

This study explored the Somali community's experiences and perceptions of autism, which is an area that had not previously been addressed in the research literature. Autism is being diagnosed at increasingly higher rates (Matson & Kozlowski, 2011) and prior research has indicated that higher rates of autism have been found in some immigrant groups (Wing, 1980; Gillberg, Schaumann, & Gillberg, 1995; Helmer, Duncan, Peat, & Mellis, 2008). Recent studies in Sweden and Minneapolis (Barnevik-Olsson, Gillberg, & Fernell, 2010; Minnesota Department of Health, 2009) have confirmed that trend in the Somali population, as well. While no known research had previously explored this topic, the findings of this study were nonetheless compatible with some of the existing research on mental and developmental disabilities in other cultural groups.

One of the main findings from this study indicated that autism is a new concept for many Somali immigrants. Part of this may be related to the finding that the Somali people view the concept of childhood development differently than it is commonly viewed in the United States. Western cultures generally view the childhood development process in a very linear structure, defined by a series of developmental milestones appropriate at certain ages. The findings of this study found that some Somalis view

childhood development in a much broader context, with less emphasis on age being associated with the normality of certain behaviors and abilities. This finding was consistent with the research literature that indicated that different cultural groups view child-rearing and child-development in many different ways (Pipher, 2002). Because autism is defined in the DSM-IV-TR (2000) as a developmental disorder first evident in childhood, it can thus be a hard concept for Somali families to understand. The idea that there is an expected universal progression of childhood development may be a foreign concept to some Somalis.

This study also found that there were some differences between Somali and American culture in expectations around the way children interact socially within their environment. Participants reported that Somali families often found the American society's expectations of childhood behavior to be more rigid and limiting than what families encountered in Somalia. Participants in this study indicated that Somali children are sometimes viewed as "hyper" by American standards. Interestingly, this is a finding that was backed up in the literature (Elmi, 1999) which indicated that Somalis traditionally did not have a word for hyperactivity, and were unfamiliar with the concept that children's behavior could be conceived as abnormally hyperactive. Providers also reported that, due to these conceptual differences, Somali families often waited longer to enroll their child in services with the belief that the delay was something the child might outgrow.

Conversely, many providers reported that one aspect of childhood development that was mutually understood between cultures was a delay in speech and language. Providers indicated that Somali families' concerns about their children's lack of language

development were often the primary reason they sought services for their child.

Providers also indicated that they were often able to use those concerns over speech development as a common ground in obtaining parental consent to enrolling children in autism-related services, even if the parents did not necessarily agree with the autism diagnosis. This finding was also consistent with some of the previous literature that suggested that mental health providers find common goals with their clients (Zhang & Bennett, 2003) and use an eco-cultural approach when working with diverse families (Welterlin & LaRue, 2007) to find ways to avoid a cultural mismatch in diagnosis and treatment (Guerin, Guerin, Diiriye, & Yates, 2004).

This study also found a prevalent belief in the Somali community that a child's autism may have been caused by factors related to the family immigrating to America. This belief is consistent with previous reports of autism being referred to as the "American disease" within the Somali community in Minnesota (McNeil, 2009). It is an interesting finding to note because previous research has established that rates of autism are significantly higher in some Somali immigrant populations (Barnevik-Olsson, Gillberg, & Fernell, 2008; Barnevik-Olsson, Gillberg, & Fernell, 2010). Although no research has found a formal causal link between immigration and autism, this is an area that may elicit future studies. Participants reported that Somali families frequently cited other beliefs regarding possible causes of autism, including vaccinations and skin lotions containing mercury, which are beliefs that have become popular in the recent past (Gorman, 2008). However, it should be noted that most peer-accepted studies to-date have been unable to corroborate a direct causal link between vaccinations, mercury, and autism (Matson & Kozlowski, 2011).

Denial, anger, and isolation were reported by participants as some common reactions that Somali families may have towards receiving an autism diagnosis for their children. These reactions may be associated with the broader stigma that mental disorders carry in traditional Somali culture. Stigma towards mental illness in the Somali population has been noted by several studies (Elmi, 1999; Schuchman & McDonald, 2004). The findings of the current study suggest that the Somali attribute the same stigma towards the condition of autism, perhaps partially out of a general lack of knowledge about the condition. It is possible that the resulting isolation that individual Somalis feel may be self-imposed due to fear of negative response and stigma from the larger community (Schuchman & McDonald, 2004). This study's findings of stigma within the Somali community are also consistent with prior research on views toward mental disorders and disability within other cultural groups (Zhang & Bennett, 2003; Welterlin & LaRue, 2007). In many other cultures, mental illness has severe implications (Pipher, 2002), and often is directly associated with labeling the mentally ill person as "crazy" (Guerin, Guerin, Diiriye, & Yates, 2004). It is possible, therefore, that some recent Somali immigrants may not necessarily realize that mental disorders and developmental delays are not as stigmatize in the same way in American society.

Several findings regarding Somali families' experiences with the autism service system emerged from this data. Participants commonly reported that the special education system was frequently the initial point of entry for many Somali families into the autism service system. This finding may be skewed by the fact that more than half of the participants in this study worked in an educational setting. Future research may be needed to test the validity of this finding.

Findings of this study indicated that several barriers exist for Somali families when trying to access services from the autism service system. Disconnects were reported between the county, medical doctors, and special education providers, as well as a consistent perception that county providers are not as responsive and helpful as families and providers would like them to be. Participants unanimously agreed that greater emphasis needs to be placed on improving the referral process of families throughout the various parts of the service system. This finding supported prior studies' suggestions of better overall coordination between Somali families and the service system (Schuchman & McDonald, 2004) and with multicultural populations in general (Zhang & Bennett, 2003).

Access to interpreters was also found to be a key factor in the way the Somali community experienced the delivery of autism services. Participants reported that the quality of service they provide to their limited-English clients is often dependent upon the availability of well-trained interpreters. Well trained, culturally competent interpreters help facilitate the communication process between providers and clients and also assist clients in understanding the service system (Schuchman & McDonald, 2004). Participants noted that interpreters need to be readily available and on site whenever services are provided. Participants noted that Somali families are often unaware of the services available to them, and without having an interpreter available, are therefore unable to ask questions and make informed decisions about their options. The findings of this study indicated that including culturally-appropriate interpreters and staff can often facilitate the trust-building process between Somali clients and their service providers.

Schuchman & McDonald (2004) previously found success when using these same techniques while treating Somali clients for mental health issues.

Implications for Social Work Practice

The findings of this study have several important implications for social work practice. First, the findings demonstrated that the availability of interpreters and culturally specific staff is important when providing accessible and quality services to Somali families of children with autism. Prior research has found that using a multi-disciplinary and multi-cultural team is important in order to effectively meet the needs of culturally diverse populations (Schuchman & McDonald, 2004). In using this type of approach, bilingual and bicultural staff can often act as the necessary link between Somali families and the service system. Service providers have found success when they are able to incorporate a culturally-similar staff person on the service team, as that person often serves as a “familiar face” to families, as well as a necessary bridge to the often-confusing service system. Social workers and other professionals who provide autism-related services should work to include appropriately trained and qualified Somali community members in the delivery of services to this population whenever possible.

Another important implication is that social workers should be aware of the stigma that surrounds autism in the Somali community and should be prudent when using diagnostic labels to avoid alienating families from services. The findings of this research indicate that service providers can draw families into the service system by reframing the treatment plan around the family’s perspective of the presenting problem and incorporating the families’ goals into treatment. For example, if a Somali family is hesitant to enroll a child in services due to reservations about an autism diagnosis for their

child, service providers may still be able to meet the family's needs by offering services related to the child's language and speech delays. This is congruent with the social work profession's values of 'meeting clients where they are at.'

Social workers should also be mindful of the barriers that Somali families experience within the autism service system. Limited English abilities and lack of knowledge of available resources were found to be some of the barriers that Somali families experience when trying to access the service system. Additionally, Somali families were found to experience the service system as disconnected and fragmented. Social workers should, therefore, advocate for more robust referral channels between providers and also advocate for systemic changes that would create a more efficient and connected system. These changes have the potential to greatly increase the quality of services Somali families may receive. Without them, Somali families may risk disenfranchisement from an already complicated and hard-to-navigate service system. Moreover, the barriers that Somali families face in ease-of-access to services may be indicative of a larger social justice issue. Social workers have the professional responsibility to advocate for equal access policies for all clients regardless of language abilities, immigration status, and so forth.

Service providers should incorporate methods to ensure their clients fully understand the service options being presented to them. Language barriers and conceptual differences between cultures can potentially lead to misunderstandings about treatment plans and services. Somali families should be provided with service information in a way they can understand so that they can make informed decisions about services. Social workers should ensure that they obtain fully-informed consent from each

client. It is not enough for a client to sign a treatment plan – they should also be able to repeat back their options, explain the potential risks and benefits of the service, and have the opportunity to ask questions. As noted earlier, use of professionally trained interpreters may be particularly helpful in situations where service providers are working with families who are not fluent in English.

Finally, social workers should be mindful of the findings that the Somali and American cultures conceptualize childhood development differently. This finding may suggest that further childhood development-related education and outreach to the Somali community is needed to help parents recognize the signs of autism. Alternatively, this finding could suggest that the service systems should work to embrace multicultural perspectives of childhood development and find innovative ways to provide education services without expecting conformity to Western concepts. This is a particularly important point for social workers, as the profession adheres to a series of ethical principles, including the respect of client autonomy.

Strengths and Limitations

Strengths. This research offered a number of strengths. Because there is minimal research regarding autism within the Somali community, and nothing specifically exploring the Somali community's experiences with autism, this research contributes to a currently limited knowledge base. In using a qualitative approach in this study, the researcher was able to gain in-depth information from participants on the topic in order to contribute detailed information to the field of literature. The use of a semi-structured interview model allowed the researcher greater flexibility to explore new or unfamiliar ideas that participants had reported. Another strength of the research was that all

participants were very knowledgeable and experienced in working with Somali families and autism, and thus they were able to add a great deal of insight to the topic.

Participants came from a variety of community settings and represented several key parts of the autism service system and this allowed for a diversity of opinions to be shared.

Limitations. There were several limitations to this research design. The sample size was relatively small, consisting of only seven participants. Therefore, the ability to generalize the findings to the entire Somali community is limited. The fact that more than half of the participants were not of Somali origin also limits the ability to generalize the findings. A striking limitation is that none of the participants were themselves Somali parents of children with autism. A research design that included Somali parents of children with autism in the sample would likely yield more representative results. While the study's sample of community professionals could speak to their own knowledge of autism in the Somali community, they were not able to speak about experiencing the autism system as a Somali parent of an autistic child firsthand. Moreover, the sample consisted of service providers, who may have a biased opinion due to their educational and professional backgrounds. Because participants were identified using snowball sampling methods, the sample was not random. Interview questions were reviewed with a research committee but were not tested for reliability. A final limitation of the study was that only professionals in the Twin Cities metropolitan area were interviewed. It is possible that professionals from other locations in Minnesota, or perhaps even in other metropolitan areas outside of Minnesota, have different opinions about the topic. This study focused only on the experiences of the Somali community in the Minneapolis/St.

Paul metropolitan area and cannot be generalized to other Somali communities outside of that geographic area.

Conclusion

This research explored the Somali community's experiences with autism through the use of interviews with service providers who work with Somali families of children with autism. Previous research in this area suggests that prevalence rates of autism are higher in immigrant populations. This trend has been found in several Somali immigrant populations, including those in Minneapolis. Findings from this study suggest that Somali families experience several barriers in accessing the autism service system. It was also found that cultural variance in perspectives of childhood development influences the way Somali families experience autism and autism-related services.

This study shows the need for autism service providers to be aware of the cultural differences in the way autism is perceived by the Somali community, so that they can effectively and appropriately engage Somali families in the service system to meet mutual goals. The need for recognizing and respecting these differences is important for effective treatment and ensuring equal access for Somali families to and within the service system.

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Appendix A

THE SOMALI COMMUNITY'S EXPERIENCES WITH AUTISM: AN EXPLORATORY STUDY OF COMMUNITY PROFESSIONALS' VIEWS

RESEARCH INFORMATION AND CONSENT FORM

ST. CATHERINE UNIVERSITY

Introduction:

You are invited to participate in a research study investigating the Somali community's experiences with autism. This study is being conducted by Jessica Kuenzli, a current Master of Social Work student at the University of St. Thomas/St. Catherine University's School of Social Work. You were selected as a possible participant in this research because of your work and perceived knowledge in working with autism in the Somali community. Please read this form and ask questions before you decide whether to participate in the study.

Background Information:

The purpose of this study is to gain a better understanding of the ways in which the Somali community is affected by autism, and the ways in which the Somali community experiences and perceives the condition. Approximately eight to ten people are expected to participate in this research. The study's methodology is a qualitative study utilizing a semi-structured interview schedule with open-ended questions. The results of the study will be interpreted using grounded theory methods, which will allow the researcher to identify themes and relevant theoretical explanations in the data. A copy of the interview questions is attached.

Procedures:

If you decide to participate, you will be asked to do the following things. You will be asked to review and sign this consent form, then participate in a one-time audio-recorded interview. The interview should last approximately 45 minutes to an hour. Your participation in this study will end at the completion of the interview session. Findings obtained from the interviews will be transcribed and presented with other clinical research projects on May 14th, 2012 at the University of Saint Thomas. Findings (with de-identified data) will also be available for review in bound copies at the University of Saint Thomas and Saint Catherine University.

Risks and Benefits:

This study as no known risks.

This study has no direct benefits.

Compensation:

There is no compensation for participation in this study. Participation is completely voluntary.

Confidentiality:

Any information obtained in connection with this study that could identify you will be kept confidential. In order to protect client confidentiality, the researcher requests that client identities are not disclosed during the interview. In any written reports or presentations, I will not include information that will make it possible to identify you or your clients in any way. The types of records I will create include audio recordings, transcripts of interviews, and consent forms of participants. These items will be kept in a locked file cabinet and in a password protected computer in the researcher's home. I will be the only one to have access to these records. I will finish analyzing the data by May 14th, 2011. I will then destroy all original reports, audio recordings and identifying information that can be linked back to you. Audio recordings will be erased and printed copies and forms will be shredded.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with the School of Social Work or St. Catherine University in any way. You have a right to refuse to answer any interview question asked of you. If you decide to participate, you are free to stop at any time without affecting these relationships, and no further data will be collected.

Contacts and questions:

My name is Jessica Kuenzli. You may ask any questions you have now. If you have any additional questions later, please feel free to contact me at [phone number redacted for publishing] or by email at [email address redacted for publishing]. You may also contact Sarah Ferguson, Ph.D., my University of Saint Thomas/Saint Catherine University research chair, [contact info redacted for publishing]. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Lynne Linder at the St. Catherine University Institutional Review Board, at (651) 690-6203, or by email at lelinder@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

I consent to participate in the study. I also agree to allow the interview to be audio-recorded for transcription and data analysis purposes.

Signature of Participant

Date

Signature of Researcher

Date

APPENDIX B

INTERVIEW QUESTIONS

1. Please tell me in what capacity you work with Somali families who have children with autism.
2. How do your Somali clients/families experience the process of receiving an autism diagnosis?
3. What happens after a Somali client/family receives a diagnosis of autism for their child?
4. In your professional opinion, how is the condition of autism perceived by the Somali community?
5. What are the needs of this population (Somali families who have children with autism?) Are these needs being met? Are there any unmet needs?
6. Does this population (Somali children with autism and/or their families) experience any barriers in accessing services for autism? If so, what are they?
7. Do any barriers exist in providing services to Somali children with autism and/or their families? If so, what are they?
8. Is there anything else you'd like me to know about this topic?